Does heart failure-specific health status identify patients with bothersome symptoms, depression, anxiety, and/or poorer spiritual well-being?

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Aims

Patients with heart failure often have under-recognized symptoms, depression, anxiety, and poorer spiritual well-being ('QoL domains'). Ideally all patients should have heart failure-specific health status and quality of life (QoL) domains routinely evaluated; however, lack of time and resources are limiting in most clinical settings. Therefore, we aimed to evaluate whether heart failure-specific health status was associated with QoL domains and to identify a score warranting further evaluation of QoL domain deficits.

Methods and results

Participants ($N = 314$) enrolled in the Collaborative Care to Alleviate Symptoms and Adjust to Illness trial completed measures of heart failure-specific health status [Kansas City Cardiomyopathy Questionnaire, KCCQ (score 0–100, 0 = worst health status)], additional symptoms (Memorial Symptom Assessment Scale), depression (Patient Health Questionnaire-9), anxiety (Generalized Anxiety Disorder-7), and spiritual well-being (Facit-Sp) at baseline. Mean $\pm$ standard deviation (SD) KCCQ score was 46.9 ± 19.3 , mean age was 65.5 ± 11.4 , and 79% were male. Prevalence of QoL domain deficits ranged from 11% (nausea) to 47% (depression). Sensitivity/specificity of KCCQ for each QoL domain ranged from 20–40%/80–96% for KCCQ ≤ 25 , 61–84%/48–62% for KCCQ ≤ 50 , 84–97%/26–40% for KCCQ ≤ 60 , and 96–100%/8–13% for KCCQ ≤ 75 . Patients with KCCQ ≤ 60 had mean $\pm$ SD 4.5 $\pm$ 2.5 QoL domain deficits (maximum 12), vs. 1.6 $\pm$ 1.6 for KCCQ > 60 ($P < 0.001$). Similar results were seen for KCCQ ≤ 25 (6.6 $\pm$ 2.4 vs. 3.3 $\pm$ 2.4), KCCQ ≤ 50 (4.8 $\pm$ 2.6 vs. 2.5 $\pm$ 2) and KCCQ ≤ 75 (4.0 $\pm$ 2.6 vs. 1.0 $\pm$ 1.2) (all $P < 0.0001$).

Conclusion

KCCQ ≤ 60 had good sensitivity for each QoL domain deficit and for patients with at least one QoL domain deficit. Screening for QoL domain deficits should target patients with lower KCCQ scores based on a clinic's KCCQ score distribution and clinical resources for addressing QoL domain deficits.

Keywords

Health status • Kansas City Cardiomyopathy Questionnaire • Heart failure • Symptoms • Depression • Anxiety • Spiritual-well being

Introduction

The care of patients with heart failure is typically centred around life-prolonging therapies and management of symptoms from congestion and low cardiac output.¹ However, patients with heart failure often

suffer from a wider range of symptoms, with a symptom burden comparable to those with advanced cancer.² Importantly, many of these symptoms are not usually ascribed to heart failure, and therefore often go unrecognized by cardiology providers.³ Standardized heart failure-specific health status assessments are becoming increasingly

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used in the routine clinical care of patients with heart failure.^{4,5} Previous investigators suggested that heart failure-specific health status measures be used to identify patients with heart failure who would benefit from a palliative care consultation based on symptom assessment scales and the Palliative Performance Scale.^{6,7} However, these studies were small, did not identify a dichotomous heart failure-specific health status score at which clinicians should act, and did not evaluate other quality of life (QoL) domains such as depression, anxiety, or spiritual well-being. In this article, we will take a broad view of the term QoL, which the World Health Organization (WHO) defines as 'an individual's perception of their position in life in the context of the culture and values systems in which they live and in relation to their goals, expectations, standards, and concerns'. The WHO goes on to specify 'physical health, psychological state, personal beliefs and social relationships' as key components to QoL.⁸ Therefore, we include bothersome symptoms not typically ascribed to heart failure, depression, anxiety, and poorer spiritual well-being, as 'QoL domain deficits'.

These QoL domain deficits are important to assess because they matter to patients⁹ and contribute to poor heart failure-specific outcomes in patients with heart failure,^{10–12} including increased hospitalization rates¹³ and mortality.^{13,14} Patients with heart failure suffer a broad range of symptoms that impact their heart failure-specific health status^{10–12} and prefer they be addressed by their cardiology providers.⁹ Depression and anxiety are prevalent among patients with heart failure,^{15,16} and increase the risk of hospitalization and mortality.^{16,17} Spirituality is an important component to illness adjustment in patients with heart failure,¹⁸ and worse spiritual well-being is associated with depression and poor quality of life.¹⁹ Taken together, these data suggest that the presence of one or more QoL domain deficits is not only important to patients but may also affects outcomes such as hospitalization and mortality.

However, time and resource constraints limit the widespread adoption of such assessments in routine clinical care.⁴ Therefore the current study sought to (i) determine the association of the Kansas City Cardiomyopathy Questionnaire (KCCQ) with 12 QoL domains: bothersome symptoms (pain, nausea, problems with sexual interest, constipation, trouble sleeping, numbness and tingling, dry mouth, cough, drowsiness), depression, anxiety, and poorer spiritual well-being in a large cohort of symptomatic patients with heart failure and (ii) to evaluate whether the KCCQ can be used as a screening tool for identifying patients with deficits in one or more QoL domains. We aimed to optimize sensitivity over specificity of the KCCQ for each QoL domain because (i) the KCCQ is being used as a screening, and not a diagnostic test in this setting and (ii) follow-up evaluation for a false positive result does not put the patient at increased risk of morbidity or mortality associated with further diagnostic testing, such as a positive cancer screening leading to a biopsy.

Methods

This was an analysis of the Collaborative Care to Alleviate Symptoms and Adjust (CASA) to Illness trial (clinicaltrials.gov NCT01739686). The trial design, methods, rationale and results have been previously published.^{20,21} Briefly, the CASA trial was an NIH-funded, three-site (academic medical centre, safety-net hospital, and Veterans Affairs hospital) clinical trial that randomized patients with heart failure and poor health

status to either a collaborative care intervention or usual care. Inclusion criteria included a prior diagnosis of heart failure (reduced or preserved ejection), poor health status (KCCQ overall summary score at a screening visit <70), and bothered by one of the study's target symptoms (pain, low mood, fatigue, shortness of breath). The trial protocol was approved by the Colorado Multiple Institutional Review Board and was regularly reviewed by an independent data and safety monitoring committee. Participants gave written, informed consent.

Demographic and clinical data were collected via chart review and patient self-report. All questionnaires were collected at baseline and at 12 months. The baseline visit was separate from the screening visit, therefore some patients, who had KCCQ <70 on the screening visit, may have had KCCQ ≥70 at study enrolment.

Heart failure-specific health status

The KCCQ is a reliable, valid, 23-item heart failure-specific health status questionnaire.²² The shorter form of the KCCQ (KCCQ-12)²³ was used to screen patients for the CASA trial and the full 23-item version was used once patients were enrolled. The KCCQ overall summary score was used in the current study, and includes domains of physical limitation, symptoms, quality of life, and social limitation. It is scored from 0 to 100; lower scores indicate worse health status. In derivation cohorts, the correlation between the overall summary score in the KCCQ-12 and full KCCQ questionnaire was 0.92.²³ The KCCQ was chosen as the health status measure of choice in this study because the scale range and scoring are intuitive to interpret and there is a short, 12-item version to improve ease of administration, and increase adherence to filling out the questionnaire. Moreover, it is endorsed by the International Consortium for Health Outcomes Measurement (<https://www.ichom.org/medical-conditions/heart-failure/>) and is increasingly being used throughout the world to monitor the value of heart failure care.

QoL domains

Symptoms

Physical symptom burden was assessed using selected items from the Memorial Symptom Assessment Scale-Short Form (MSAS-SF).²⁴ The MSAS was originally developed in cancer patients, but is also validated in heart failure.²⁵ The CASA trial design did not include the full 32-item MSAS questionnaire because many of the MSAS questions overlapped with other measures. Patients were asked about nine symptoms that are not assessed by the KCCQ: pain, nausea, difficulty sleeping, constipation, dry mouth, cough, numbness/tingling, problems with sexual interest, and feeling drowsy. These symptoms were chosen because they are common among patients with heart failure.^{11,26,27} Similar to other studies of patients with heart failure and other chronic conditions, symptoms were reported individually (rather than part of a composite score) to make them more clinically actionable.^{11,26–29} Patients first indicated whether they experienced the symptom, and if so, were asked to rate how bothersome the symptom was from 0 (not at all bothersome) to 4 (very bothersome). In this analysis, we used a score of either 3 (quite a bit bothersome) or 4 to indicate that the symptom was bothersome.

Depression, anxiety, and spiritual well-being

Depressive symptoms were assessed using the Patient Health Questionnaire-9 (PHQ-9), a reliable, validated, 9-item instrument designed to screen for depression.³⁰ The PHQ-9 is scored from 0 to 27; a positive screen for depression is a PHQ-9 score ≥10.

Anxiety was assessed using the Generalized Anxiety Disorder-7 (GAD-7) questionnaire.³¹ The GAD-7 is a reliable, validated 7-item instrument designed to screen for anxiety disorder. The GAD-7 is scored

from 0 to 21, with higher scores indicating worse anxiety symptoms. A positive screen for anxiety is a GAD-7 score ≥ 10 .

Spiritual well-being was measured using the Facit-Sp.³² The Facit-Sp is a 12-item questionnaire that is scored from 0 to 48, with higher scores indicating better spiritual well-being. Questions are answered on a Likert scale ranging from 0 to 4, with 4 indicating better spiritual well-being. The Facit-Sp was developed and validated in large populations of medically ill patients.^{32,33} The Facit-Sp was chosen in this study because of its previous use in studies of patients with heart failure.^{27,34,35} Facit-Sp mean scores range from 32 to 37 in heart failure populations, with higher scores in less severe heart failure.^{19,34,35} Current literature does not define a dichotomous threshold indicating poorer spiritual well-being,^{32,36} and to our knowledge, there is no precedent for handling the Facit-Sp as a dichotomous variable. Given the importance of spiritual well-being to patients, and its association with depression and heart failure-specific health status, we chose to include it in the current study. Facit-Sp scores had a skewed distribution, therefore we used scores lower than our population median (median = 31) to define poorer spiritual well-being. This value corresponds to an answer of between 1 and 2 on the Likert scale (e.g. answering 'a little bit' or 'somewhat' to the statement 'I feel peaceful').

Statistical analysis

Differences between groups were assessed using Student's *t*-test or χ^2 test for continuous and categorical variables, respectively. Pearson correlation coefficients were calculated to quantify the associations between the KCCQ and each QoL domain. Correlations were reported with and without pre-determined covariates: age, sex, race, ejection fraction, and education.

We initially evaluated 25, 50, and 75 as potential thresholds for identifying the majority of patients with in at least one QoL domain deficit, as these have been previously identified as clinically salient KCCQ score groupings that correlate with mortality, hospitalization rates and New York Heart Association class.^{13,22} After examining the results, we decided to also assess a KCCQ threshold of 60 to improve the capture of patients with at least one QoL domain deficit, while also dividing the population in a meaningful manner.

In the overall CASA population, KCCQ scores started low (mean $\pm$ standard deviation 46.9 ± 19.3 at baseline) and rose to 52.7 ± 22 at 12 months ($P = 0.02$). Therefore, we also examined the performance of the different KCCQ thresholds at 12 months, when the proportion of patients at each KCCQ threshold would be different.

All analyses were performed using SAS Studio or STATA v 14.2.

Results

The study population had a mean age of 65.5 years, was mostly male (79%), and about half of patients had preserved or mildly reduced ejection fraction and overall had poor health status (Table 1). Of the symptoms measured by the MSAS-SF, pain and difficulty sleeping were rated as the most bothersome. The QoL domain deficits with the highest prevalence at baseline were poorer spiritual well-being ($N = 171$; 54%), depression ($N = 148$; 47%), pain ($N = 136$; 43%), and problems with sexual interest ($N = 129$; 41%), whereas nausea had the lowest prevalence ($N = 34$; 11%). Over 1 year of follow-up, 19 (6%) patients died and 60 (19%) did not complete 12-month follow-up surveys.

The KCCQ was significantly correlated with each QoL domain at baseline and 12 months (Table 2). Of the QoL domains, depression and anxiety had the strongest correlation with KCCQ ($R > 0.5$;

Table 1 Baseline characteristics of the overall cohort

	Total (N = 314)
Age	65.5 $\pm$ 11.4
Female	67 (21)
Non-white	87 (28)
Hispanic	33 (10.5)
Ejection fraction ^a	
Normal ($\geq 50\%$)	121 (40.5)
Mildly reduced (40–49%)	46 (15.4)
Moderately reduced (30–39%)	52 (17.4)
Severely reduced ($< 30\%$)	80 (27.0)
Education	
High school or GED	196 (62.6)
College or any graduate work	98 (31.3)
Overall KCCQ	46.9 $\pm$ 19.3
QoL domains, mean $\pm$ SD (prevalence)	
Pain	2.6 $\pm$ 0.96 (43)
Nausea	1.9 $\pm$ 1.1 (11)
Sleep	2.5 $\pm$ 1.1 (34)
Constipation	2.1 $\pm$ 1.2 (13)
Cough	2.1 $\pm$ 1.1 (22)
Dry mouth	2.3 $\pm$ 1.1 (31)
Problems with sexual interest	3.0 $\pm$ 1.2 (41)
Drowsy	2.1 $\pm$ 0.99 (27)
Numbness	2.4 $\pm$ 1.1 (32)
Depression (PHQ-9)	9.8 $\pm$ 5.9 (47)
Anxiety (GAD-7)	5.7 $\pm$ 5.2 (23)
Spiritual well-being (Facit-Sp)	29.5 $\pm$ 8.2 (54)

Data are presented as mean $\pm$ SD or N (%).

—Facit-Sp, Functional Assessment of Chronic Illness Therapy-Spiritual Well-being scored from 0 to 48, with 0 indicating worst possible spiritual well-being; GAD-7, Generalized Anxiety Disorder 7—scored from 0 to 21, with 0 indicating no anxiety symptoms; KCCQ, Kansas City Cardiomyopathy Questionnaire—scored from 0 to 100, with 0 indicating worse health status; PHQ-9, Patient Health Questionnaire 9—scored from 0 to 27, with 0 indicating no depressive symptoms; QoL domains, quality of life domains.

^aLeft ventricular ejection fraction was available for 150 usual care and 149 intervention patients. Normal $\geq 50\%$, mildly reduced 40–49%, moderately reduced 30–39%, and severely reduced $> 30\%$.

Table 2), followed by pain, trouble sleeping, nausea, and poorer spiritual well-being ($R > 0.3$; Table 2).

Comparing KCCQ thresholds for sensitivity and specificity for deficits in QoL domains

Tables 3 and 4 demonstrate the area under the curve for each QoL domain, and the sensitivity and specificity for four different KCCQ thresholds (25, 50, 60, and 75) at baseline and 12 months, respectively. KCCQ ≤ 25 had poor sensitivity for each individual QoL domain and had low sensitivity for identifying patients with any one QoL domain deficit (16% and 22% at baseline and 12 months, respectively). Although KCCQ ≤ 75 had excellent sensitivity for each QoL domain and for patients with any one QoL domain deficit (95% and 89% at baseline and 12 months, respectively), it did not divide the group

Table 2 Pearson partial correlation coefficients for each QoL domain and the KCCQ at baseline and 12 months

	Baseline	12 months
Pain	-0.29 ($P < 0.0001$)	-0.44 ($P < 0.0001$)
Nausea	-0.34 ($P = 0.0006$)	-0.41 ($P = 0.0006$)
Trouble sleeping	-0.37 ($P < 0.0001$)	-0.32 ($P = 0.0002$)
Constipation	-0.27 ($P = 0.0030$)	-0.34 ($P = 0.0022$)
Dry mouth	-0.35 ($P < 0.0001$)	-0.41 ($P < 0.0001$)
Cough	-0.30 ($P < 0.0001$)	-0.15 (0.12)
Numbness/tingling	-0.21 ($P = 0.0027$)	-0.24 ($P = 0.0039$)
Problems with sexual interest	-0.21 ($P = 0.0036$)	-0.19 ($P = 0.04$)
Drowsy	-0.33 ($P < 0.0001$)	-0.39 ($P < 0.0001$)
Depression	-0.59 ($P < 0.0001$)	-0.64 ($P < 0.0001$)
Anxiety	-0.50 ($P < 0.0001$)	-0.47 ($P < 0.0001$)
Spiritual well-being	0.30 ($P < 0.0001$)	0.36 ($P < 0.0001$)

meaningfully (i.e. only 7% of patients at baseline had KCCQ >75). KCCQ ≤50 divided the population in a meaningful manner (i.e. 56% of patients at baseline had KCCQ ≤50) but had only moderate sensitivity for each domain, as well as for patients with any one QoL domain deficit (60% and 55% at baseline and 12 months, respectively). KCCQ ≤60 divided the population in a meaningful manner (76% of patients at baseline had KCCQ ≤60), with higher sensitivity for each QoL domain and for patients with any one QoL domain deficit (81% and 72% at baseline and 12 months, respectively) compared with KCCQ ≤50.

The proportion of patients above a given KCCQ threshold that have only 0 or 1 QoL domain deficits increases with higher KCCQ thresholds (Figures 1–4). Lower KCCQ thresholds identified patients with multiple QoL domain deficits compared with higher KCCQ thresholds (Figures 1–4). At baseline, patients with KCCQ ≤25 had an average of 6.6 ± 2.4 QoL domain deficits (out of a total of 12), whereas patients with KCCQ >25 had an average of 3.3 ± 2.4 deficits ($P < 0.0001$). Patients with KCCQ ≤50 had an average of 4.8 ± 2.6 QoL domain deficits vs. 2.5 ± 2 if KCCQ >50 ($P < 0.0001$). Patients with KCCQ ≤60 had an average of 4.5 ± 2.5 QoL domain deficits vs. 1.6 ± 1.6 deficits if KCCQ >60 ($P < 0.0001$). Patients with KCCQ ≤75 had an average of 4.0 ± 2.6 QoL domain deficits vs. 1.0 ± 1.2 deficits if KCCQ >75 ($P < 0.0001$). At 12 months, patients with KCCQ ≤25 had an average of 4.4 ± 2.7 QoL domain deficits, whereas patients with KCCQ >25 had an average of 2.8 ± 2.2 deficits ($P < 0.0001$). Patients with KCCQ ≤50 had an average of 4.1 ± 2.4 QoL domain deficits, vs. 2.0 ± 1.8 if KCCQ >50 ($P < 0.0001$). Patients with KCCQ ≤60 had an average of 3.8 ± 2.3 QoL domain deficits vs. 1.7 ± 1.8 if KCCQ >60 ($P < 0.0001$). Patients with KCCQ ≤75 had an average of 3.4 ± 2.3 QoL domain deficits vs. 1.1 ± 1.2 if KCCQ >75 ($P < 0.0001$).

Discussion

Although patients with heart failure can have bothersome symptoms, depression, anxiety, and poorer spiritual well-being, time and

resource constraints in the typical cardiology outpatient encounter make it impractical to formally assess each of these QoL domains in each patient. Accordingly, a method for screening patients in routine clinical care could help identify patients who warrant more attention to other QoL domains. The wide range of QoL domains measured in the current study were highly correlated with the KCCQ. KCCQ scores ≤60 had better sensitivity than KCCQ scores ≤50 for each additional QoL domain, while still dividing the population in a meaningful manner. These data suggest that KCCQ ≤60 has the potential to serve as a method for identifying a subset of patients who should undergo further assessment for QoL domain deficits in the study population (i.e. using a KCCQ score threshold of ≤60, we would eliminate 24% of the study population from further assessment). However, the choice of ideal KCCQ score threshold should be tailored to each clinical setting, taking into account clinical resources for caring for deficits in QoL domains and the distribution of health status scores in a given population. Any KCCQ threshold should be conceptualized as a risk stratification tool, so that resources for assessing patients for QoL domain deficits can be allocated more efficiently.

The 12 QoL domain deficits measured in this article are important to consider in the clinical setting because they matter to patients⁹ and are associated with poor heart failure-specific health status, which in turn is associated with increased risk of hospitalization¹³ and mortality.^{13,14} More research is needed to assess whether measuring and improving QoL domain deficits improves hospitalization and mortality, however, clinicians should still be focused on these issues because they are important to patients.

Although the use of the KCCQ and other heart-failure specific health status questionnaires is now a conventional component of heart failure clinical trials, their incorporation into routine clinical care has lagged, despite broad support.^{4,37,38} One reason for this slow adoption may be the perception that the KCCQ score does not always signal a clear management decision in a patient's care. The current study provides a potential action for clinicians to take, based on the result of heart failure-specific health status scores.

When a clinician identifies a QoL domain deficit in a patient with heart failure, treatment options are more apparent for some QoL domains compared with others. For example, depression and anxiety may respond to psychotherapy even though clinical trials of antidepressant medications in heart failure have been disappointing.^{39–42} Treatment of bothersome symptoms primarily requires astute clinical judgement, in which the clinician investigates the cause of the bothersome symptom, and offers treatments options that may or may not be disease specific, and could be pharmacologic or non-pharmacologic. Addressing poorer spiritual well-being has primarily been studied in the cancer literature,⁴³ signalling an evidence gap for patients with heart failure. Despite this evidence gap, we chose to include spiritual well-being in the current study because it may eventually have a larger evidence base supporting its use and because it is important to patients.

Strengths and limitations

This study has several notable strengths. First, extensive data characterizing patients' health status, bothersome symptoms, depressive and anxiety symptoms, and spiritual well-being were collected from patients with heart failure treated in three diverse healthcare settings. These data are difficult to collect in full in observational settings,

Table 3 Sensitivity and specificity of QoL domains by four different KCCQ thresholds using baseline data

	N = 314	KCCQ ≤25 threshold (N = 47)		KCCQ ≤50 threshold (N = 175)		KCCQ ≤60 threshold (N = 238)		KCCQ ≤75 threshold (N = 291)	
	AUC	Sensitivity	Specificity	Sensitivity	Specificity	Sensitivity	Specificity	Sensitivity	Specificity
Pain	0.71	26%	93%	73%	57%	93%	37%	99%	12%
Nausea	0.72	35%	88%	82%	48%	94%	26%	100%	8%
Trouble sleeping	0.68	27%	91%	68%	51%	89%	31%	99%	11%
Constipation	0.66	34%	88%	73%	47%	85%	26%	98%	8%
Dry mouth	0.69	25%	89%	74%	52%	92%	31%	99%	10%
Cough	0.65	30%	89%	67%	47%	87%	27%	96%	8%
Numbness and tingling	0.65	20%	87%	70%	51%	85%	29%	96%	9%
Problems with sexual interest	0.62	22%	90%	62%	49%	86%	31%	98%	11%
Drowsiness	0.70	28%	90%	72%	50%	94%	31%	99%	10%
Depression	0.78	27%	96%	76%	62%	93%	40%	99%	13%
Anxiety	0.80	40%	92%	84%	52%	97%	30%	100%	9%
Poorer spiritual well-being	0.60	19%	90%	61%	51%	84%	34%	96%	11%

Data are presented as N (%) or mean ± SD.

AUC, area under the curve; KCCQ, Kansas City Cardiomyopathy Questionnaire; SD, standard deviation.

Table 4 Sensitivity and specificity of QoL domains by 4 different KCCQ thresholds using 12 months data

	N = 235	KCCQ ≤25 threshold (N = 45)		KCCQ ≤50 threshold (N = 120)		KCCQ ≤60 threshold (N = 154)		KCCQ ≤75 threshold (N = 198)	
	AUC	Sensitivity	Specificity	Sensitivity	Specificity	Sensitivity	Specificity	Sensitivity	Specificity
Pain	0.72	27%	85%	71%	60%	83%	44%	93%	21%
Nausea	0.74	39%	82%	78%	51%	89%	36%	100%	17%
Trouble sleeping	0.66	27%	83%	62%	53%	82%	40%	93%	19%
Constipation	0.68	41%	84%	70%	51%	78%	36%	96%	17%
Dry mouth	0.73	30%	84%	73%	56%	86%	41%	96%	20%
Cough	0.64	24%	82%	65%	51%	82%	37%	97%	18%
Numbness and tingling	0.67	24%	82%	63%	53%	80%	39%	92%	18%
Problems with sexual interest	0.69	24%	84%	66%	58%	78%	42%	95%	22%
Drowsy	0.74	28%	83%	74%	26%	86%	39%	98%	19%
Depression	0.80	30%	86%	75%	62%	89%	47%	99%	23%
Anxiety	0.73	34%	84%	71%	53%	79%	37%	97%	18%
Poorer spiritual well-being	0.64	25%	89%	59%	60%	74%	47%	90%	23%

Data are presented as N (%) or mean ± SD.

AUC, area under the curve; KCCQ, Kansas City Cardiomyopathy Questionnaire; SD, standard deviation.

therefore, the completeness of these data is a notable strength. Second, this study included patients with preserved and reduced ejection fraction, increasing its generalizability to the broader heart failure population. Third, we were able to show similar results at two time points.

There are, however, several limitations that should be considered in interpreting the current study. The first is that CASA specifically recruited participants with low KCCQ, limiting broader application. Our population was younger and predominantly male and white, which also limits generalizability of our findings. Second, there was

loss to follow-up at 12 months, but this was not large (N = 60; 19%) and the analyses were cross-sectional. Third, our definition of QoL domains included individual questions from the MSAS instead of taking the entire 32-item MSAS questionnaire as a whole and we may have not assessed other meaningful deficits. Fourth, there is not a clear, dichotomous definition for poorer spiritual well-being using the Facit-Sp, therefore, we used the median value of our population. Finally, this study focuses on one health status measure in heart failure. While the KCCQ is widely used, there are other heart failure health status measures available.

Figure 1 (A) Percent of patients with Kansas City Cardiomyopathy Questionnaire ≤25 by number of quality of life domain deficits, N = 46 (15%). (B) Percent of patients with Kansas City Cardiomyopathy Questionnaire >25 by number of quality of life domain deficits, N = 268 (85%).

Figure 2 (A) Percent of patients with Kansas City Cardiomyopathy Questionnaire ≤50 by number of quality of life domain deficits, N = 140 (45%). (B) Percent of patients with Kansas City Cardiomyopathy Questionnaire >50 by number of quality of life domain deficits, N = 174 (55%).

Future directions: research

Future areas for research include validation of our results in broader patient populations—i.e. in patients with a wider range of health status scores, and in populations of older adults, women and racial and ethnic minorities. Future research should also focus on improving the treatments available to patients suffering from each of the QoL domain deficits, particularly spiritual well-being. Spiritual interventions that help ground patients' sense of self or purpose despite the unpredictability of heart failure exacerbations and the uncertainty of when one might suffer sudden cardiac death or pump failure should be considered for heart failure patients with poorer spiritual well-being. Interventions fostering meaning and direction may be adapted for this purpose from the cancer literature.⁴⁴ Future research should also focus on the effect of treatments for QoL domain deficits on

downstream hospitalization or mortality outcomes. Finally, future research should also focus on improving processes of care for patients with poor health status and QoL domain deficits.

Future directions: clinical care

Although the importance of heart failure-specific health status is well-documented over the past two decades, its use in routine clinical care is inconsistent.⁴ Therefore, the expectation that clinicians will widely adopt assessment for QoL domain deficits in addition to health status measurement in routine clinical care is not realistic. Barriers to collection of health status data include time and resource constraints, both of which are also expected to limit widespread adoption of broader QoL domain deficit assessments. Therefore, the findings of the current study should

Figure 3 (A) Percent of patients with Kansas City Cardiomyopathy Questionnaire ≤ 60 by number of quality of life domain deficits, $N = 76$ (24%). (B) Percent of patients with Kansas City Cardiomyopathy Questionnaire > 60 by number of quality of life domain deficits, $N = 238$ (76%).

Figure 4 (A) Percent of patients with Kansas City Cardiomyopathy Questionnaire ≤ 75 by number of quality of life domain deficits, $N = 24$ (8%). (B) Percent of patients with Kansas City Cardiomyopathy Questionnaire > 75 by number of quality of life domain deficits, $N = 290$ (92%).

be applied to each clinical setting in a tailored fashion. For example, for practices not routinely collecting health status data on each patient, an initial step to improving the patient-centredness of care is implementation of routine health status measurement in patients with heart failure. In practices that already collect heart failure-specific health status on each patient, the first step is to determine their patients' KCCQ scores and their capacity to do more detailed QoL assessments. The next step is to consider which QoL domains the practice has the capability of treating or referring for expert consultation. The greater the capacity of these resources, the higher the KCCQ cut-off for screening for additional QoL domain deficits could be. Practices with patient populations similar to ours may use our recommended cut-off of KCCQ ≤ 60 as a starting point for identifying

additional QoL domain deficits among patients with heart failure, although lower scores would increase the yield of more extensive QoL assessments.

This approach of individualizing the KCCQ cut-off at which additional QoL domain deficit screening should occur is analogous to the recommended use of the PHQ-9 when it comes to depression screening. The PHQ-9 is scored on a continuous scale, with higher scores indicating worse depressive symptoms. Indeed, clinics that choose a higher (i.e. 12–15) score threshold for their depression screen have fewer false positives than clinics using the widely adopted PHQ-9 score cut-off ≥ 10 .⁴⁵ Similarly, the choice of a health status score cut-off requires investigators and clinicians to choose between sensitivity and specificity, or false positive rate vs. false negative rate. In a meta-analysis of 17 studies analysing the relationship between

heart failure-specific health status and mortality, there was no one uniform definition of 'poor' or 'good' heart failure-specific health status among the 17 studies.¹⁴ Some studies divided patients into quartiles or tertiles, others chose ranges of scores, or the middle value (e.g. KCCQ score above vs. below 50), and others chose a different dichotomous cut-off based on their population's distribution.¹⁴

Conclusion

Ideally, all patients with heart failure should be evaluated for bothersome symptoms, depression, anxiety and poorer spiritual well-being, in addition to measuring the KCCQ; however, such extensive evaluation is not feasible for every patient in most clinical settings due to time and resource constraints. Therefore, scarce clinical resources for measuring deficits in QoL domains may be best allocated to patients with lower KCCQ scores. Although KCCQ ≤ 60 had good sensitivity for each QoL domain deficit and for patients with at least one QoL domain deficit in our study population, the ideal KCCQ threshold will depend on the individual clinical setting. This threshold should be chosen based on population-specific health status score distribution and clinical resources for assessing and potentially treating QoL domain deficits.

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